

CONSUMERS' VIEW

After Bristol: putting patients at the centre*

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Many of the 198 recommendations made by the Bristol inquiry urged doctors to include patients as active participants in their own care. Angela Coulter discusses how these recommendations can be turned into reality

The public inquiry into failures in the performance of surgeons involved in heart surgery on children at the Bristol Royal Infirmary between 1984 and 1995 made 198 recommendations on how to prevent failures in the future. The pre-eminent recommendations urged doctors to:

- Involve patients (or their parents) in decisions
- Keep patients (or parents) informed
- Improve communication with patients (or parents)
- Provide patients (or parents) with counselling and support
- Gain informed consent for all procedures and processes
- Elicit feedback from patients (or parents) and listen to their views
- Be open and candid when adverse events occur.¹

These recommendations are fine rhetoric, but how can they be turned into reality?

Improving responsiveness to patients has been a goal of health policy in the United Kingdom for several decades. Until now, most initiatives in this area have failed to change noticeably the everyday experience of most patients in the NHS. The harsh realities of budgetary pressures, staff shortages, and other managerial imperatives tend to displace good intentions about informing and involving patients, responding quickly and effectively to patients' needs and wishes, and ensuring that patients are treated in a dignified and supportive manner. This is the essence of patient centred care, and most health professionals strive to achieve it. Many clinical staff, however, feel that demands for them to improve efficiency and productivity have restricted their ability to offer the time and empathy that patients need and hope for.²

A new urgency is in the air, though—improving patients' experiences is much higher up the agenda. In 2000 the British government made this the central theme of its plan for the NHS. It announced that incentive systems would be realigned to encourage improvements in performance and that patients' feedback would be incorporated into the star rating system for performance indicators.³ This carrot and stick approach may be needed to kick start the move towards greater responsiveness to patients, but deeper reasons lie behind the need for healthcare providers to move in this direction.

WHY DO WE NEED GREATER RESPONSIVENESS TO PATIENTS?

Meeting expectations

That public expectations are rising faster than the ability of health services to meet them is now a cliché. This fact describes, however, one of the most important ironies of modern health care. Public spending on health care is increasing much faster than inflation in most countries, and effective treatments are available more widely than ever before. At the same time, public pessimism about the future of health systems is growing.⁴ Although patients' overall satisfaction with the NHS has fluctuated in recent years, inpatients' satisfaction with hospital care has been decreasing since 1989.^{5,1}

The British public continues to strongly support the principle that health care should be funded by taxes. Memories of the fragmented and inequitable system that preceded its introduction are fading, however, and the NHS can no longer trade on people's gratitude. Tolerance of long waiting times, lack of information, uncommunicative staff, and failures to seek patients' views and take account of their preferences is wearing thin. Politicians recognise this—hence their goal of modernising the system by encouraging greater responsiveness to patients. In the long run, the survival of the NHS depends on the extent to which this goal can be achieved.

Providing appropriate care

Provision of information to and involvement of the patient is at the heart of the patient centred approach to health care. If doctors are ignorant of patients' values and preferences, patients may receive treatment that is inappropriate to their needs. Studies have shown that doctors often fail to understand patients' preferences.⁶ The quality of clinical communication is related to positive health outcomes.⁷ Patients who are well informed about prognosis and treatment options, including potential harms and side effects, are more likely to adhere to treatments and have better health outcomes.⁸ They are also less likely to accept ineffective or risky procedures.⁹ To maximise the benefit of treatment, doctors need to give patients clear explanations of the nature of clinical evidence and its interpretation.

Evidence supports the shift towards shared decision making, in which patients are encouraged to express their views and participate in

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Summary points

- The Bristol inquiry recommended that patients must be at the centre of the NHS and must be treated as partners by health professionals—as “equals with different expertise”
- The survival of the NHS depends on the extent to which it can improve responsiveness to patients’ needs and wishes
- Appropriateness and outcome of care can be improved by engaging patients in treatment and management decisions
- Safety could be improved and complaints and litigation reduced if patients were actively involved in their own care
- Regular, systematic feedback from patients is essential to improve quality of care and for public accountability

Box 1 Relatively common prescribing errors

- Poor compliance caused by prescribers failing to elicit patients’ preferences and beliefs about medicines
- Poor compliance caused by prescribers failing to explain why a drug is being prescribed and how it is supposed to work
- Inappropriate drugs or dosages caused by poor communication between doctors and patients about contraindications or adverse reactions
- Failure to convey essential information to patients about how and when to take their drugs
- Failure to discuss common side effects, so that patients are ill prepared to cope with these and to recognise unexpected problems
- Errors resulting from problems occurring when medical records are transcribed (these could be avoided if patients were encouraged to check their notes)

making clinical decisions. The key to successful doctor-patient partnerships is to recognise that patients are also experts. Doctors are—or should be—well informed about diagnostic techniques, the causes of disease, prognosis, treatment options, and preventive strategies. But only patients know about their experience of illness and their social circumstances, habits, behaviour, attitudes to risk, values, and preferences. Both types of knowledge are needed to manage illnesses successfully, and the two parties must be prepared to share information and make joint decisions, drawing on a sound base of evidence. Studies of general practice consultations in the United Kingdom found little evidence that doctors and patients currently share decision making in the recommended manner.^{10–11} Interest in this approach is growing among clinicians, however, particularly among those involved in primary care. Training is now required to equip doctors with the communication skills needed to help patients play a more active role.¹²

Ensuring patient safety

Doctors could reduce the incidence of medical errors and adverse events by actively involving patients. Patients who know what to expect in relation to quality standards can check on the appropriate performance of clinical tasks. For example, prescribing errors are relatively common (box 1),¹³ but many might be avoided if patients were more actively engaged in their own care. Better design of drug information leaflets and drug packaging could help too—patients should be involved in reviewing and redesigning these.¹⁴

Patients should be encouraged to review their notes, including referral letters and test results. In its plan for the NHS, the British government announced its intention to give all patients access to their electronic health records by 2004. Electronic access has the potential to significantly improve communication and accuracy of records, but a daunting number of technical and cultural barriers need to be overcome

before this goal can be achieved. The scheme is currently being piloted in general practice as part of the electronic record development and implementation programme.¹⁵ A feasibility study found that patients like the idea of electronic access.

Reducing complaints and litigation

Poor communication and failure to take account of the patient’s perspective are at the heart of most formal complaints and legal actions. Error rates could be reduced by an approach that is more patient centred; such an approach could also do much to ameliorate the adverse effects of errors if they do occur. A survey of 227 litigants who sued healthcare providers found that the overwhelming majority were dissatisfied with the nature and clarity of the explanations they were given and the lack of sympathy displayed by staff after the incident.¹⁶ In some cases, litigation might have been avoided altogether if staff had dealt with patients more sensitively after the incident.

Procedures used to gain informed consent often fall short of the ideal. Many involve a hasty discussion between a patient and a junior doctor, whose sole aim is to get a signature on a form. Options and alternatives are rarely discussed with the patient (or parent), and the “consent” implied by the signature cannot be said to be truly informed.¹⁷ Doctors who fail to provide full and balanced information about the risks and uncertainties of procedures and treatments can create unrealistic expectations; these may be the reason for the United Kingdom’s rising rates of litigation. Patients are often given a biased and highly optimistic picture of the benefits of medical care.¹⁸ For patients encouraged to believe that there is an effective pill for every illness or that surgery is free of risk, it is no wonder that the reality is often disappointing. Misplaced paternalism that tries to “protect” patients from the bad news merely fuels false hopes and does no one—patient or clinician—any good in the long run.

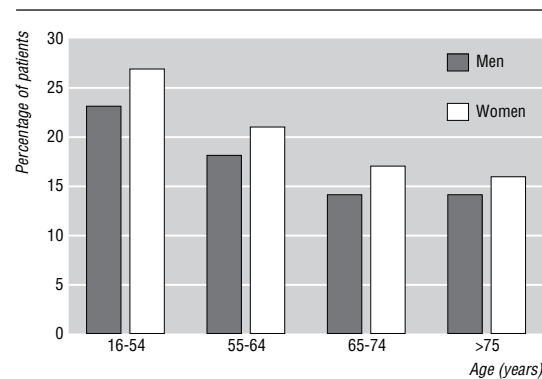
Encouraging self reliance

The paternalistic manner in which health care is currently delivered tends to foster demand, instead of encouraging self reliance. All too often patients are treated like children who need to be told what to do and to be reassured, rather than as responsible adults capable of assimilating information and using it to make informed choices. Paternalism fosters passivity and dependence, saps self confidence, and undermines people’s ability to cope. Instead of treating patients as passive recipients of medical care, it is much more appropriate to view them as partners or coproducers.¹⁹ Their input is essential to defining and understanding the problem, identifying possible solutions, and managing the illness.

Patients who are to be treated as coproducers need to be given the tools for the job. When patients are provided with unbiased, evidence based information about treatment options, likely outcomes, and self care, they usually make rational choices that are often more conservative and involve less risk than their doctors would choose.²⁰ For example, American patients given full information about the pros and cons of screening for prostate specific antigen to detect prostate cancer were less likely to undergo the test than those who were not fully informed.⁹ Appropriate and cost effective use of health services could be encouraged by investing in tools to help patients make evidence based decisions.²¹ These decision aids must be provided by reliable, independent sources that the public trust. Some public funding will be necessary—the pharmaceutical industry should not be left to make all the running.

Quality improvement

If we want to centre quality improvement efforts on the needs and wishes of patients, we must first understand how things look through their eyes, and those of their carers. Healthcare



Percentage of 84 500 patients with coronary heart disease who did not feel sufficiently involved in decisions about their care. Data from National Surveys of NHS Patients. Coronary Heart Disease 1999

providers have measured patients' satisfaction for many years. Often, however, these surveys have been conceptually flawed and methodologically weak, with the focus on managers' agendas rather than the topics most important to patients.²²

A more valid approach is to ask patients to report in detail on their experiences by asking them specific questions about whether or not certain processes and events occurred during a specific episode of care.²³ From December 2001, a new programme of surveys in NHS trusts has adopted this approach. Systematic feedback from patients, gained with high quality surveys, will generate information that is more pertinent to patients and healthcare providers at the front line than existing data systems. The success of these surveys will depend on how willing healthcare providers are to use the results to introduce initiatives to improve quality.

Public accountability

The high cost of health care and its demands on the public purse have led to calls for healthcare facilities to be more accountable to the public. This demand has resulted in the publication of performance indicators that allow healthcare facilities to be compared. These performance indicators are intended to provide information to be used to determine priorities for quality improvements as well as a detailed account of how public funds have been used.

Public access to data on the quality of care among different healthcare providers has developed much further in the United States and Canada than in the United Kingdom. However, hospital report cards and physician profiles are now being promoted in the United Kingdom. Commercial websites, such as Dr Foster (home.drfooster.co.uk), encourage the public to seek and use systematic information on the quality of health care. The establishment of new mechanisms to promote choice and accountability—such as the requirement that each hospital and primary care trust publishes a prospectus for patients—will further boost these efforts. This strategy is not without risks, not least that providers will find ways of “gaming” the system to make their performance look better than it actually is. It is by no means inevitable that the trend towards public disclosure will encourage providers to refocus their efforts on quality improvement.²⁴

SUMMARY

The lessons learned in the Bristol inquiry were clearly stated in the report. The changes demanded were well founded and are achievable. What is needed now is clear leadership from the clinical professions, investment in information and training, and a willingness to change established modes of working (box 2).

Box 2 Tools to empower patients

- Recognise patients' expertise, values, and preferences
- Offer informed choice, not passive consent
- Training in shared decision making
- Evidence based decision aids for patients
- Public education on interpreting clinical evidence
- Patient access to electronic health records
- Surveys of patients' experience to prioritise quality improvements
- Openness and empathy with patients (or parents) after medical errors have occurred
- Public access to comparative data on quality and outcomes

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